TOPICS IN REVIEW

Who should know about our genetic makeup and why?

Tuija Takala
Research fellow
Department of Philosophy
University of Turku
Turku, Finland
Heta Aleksandra Gylling
Senior research fellow
Academy of Finland
and
Docent of practical philosophy
Department of Moral and Social Philosophy
University of Helsinki
PO Box 24
Helsinki, Finland

Correspondence to:
Dr Gylling
heta.gylling@helsinki.fi

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Recent developments in biology have made it possible to acquire more and more precise information concerning our genetic makeup. Although we have only begun to see the most far-reaching effects of these developments and the completion of the Human Genome Project, scientists can even today identify a number of genetic disorders that may cause illness and disease in their carriers. The improved knowledge regarding the human genome will, it is predicted, soon make diagnoses more accurate, treatments more effective, and thereby considerably reduce and prevent unnecessary suffering. The knowledge can also be, however, depending on the case, futile, distressing, or plainly harmful. We propose to answer in this article the dual question: who should know about our genetic makeup and why? Through an analysis of prudential, moral, and legal grounds for acquiring the information, we conclude that, at least on the levels of law and social policy, practically nobody is either duty-bound to receive or entitled to have that knowledge.

WHO HAS AN INTEREST IN THE KNOWLEDGE, AND ON WHAT GROUNDS?

Four groups of people may want or need to know about people's genetic composition. First, individuals can have an interest in being aware of all important aspects of their health status, including the possibility that they nurture genetic disorders that can lead, later in life, to serious disease or early death. There are various studies on people's attitudes toward genetic testing. The ambiguity people have toward genetic knowledge in general seems to be the common result. When people are asked whether they would like to be tested, they tend to say yes, but when it comes to actual testing, they are less keen to participate.[1,2]

Second, various people are—or can become—genetically linked and consequently have an interest in the knowledge. These include family members and especially those with whom people intend to have children.

Third, individuals and groups who enter into contracts, agreements, and economic arrangements may have an interest in knowing about others' genetic makeup. This category embraces at least employers, employees, banks, insurance companies. and business associates.

Fourth, society as a whole can have an interest in the composition of people's genes, both because individuals' health status can influence the contribution they make and because the public authorities may need the information to plan more efficient health care services. In each group, the motives differ, and the cases for disclosing vary considerably in strength.

Regarding the question of motivation, the term *should* in the question "Who should know?" can be interpreted in 3 ways. *Prudentially* speaking, to say that individuals should act in a specified manner is to say that the actions in question tend to promote the long-term self-interest of these individuals. From the standpoint of *morality,* people should do what is right and avoid doing what is wrong. The rightness and wrongness of actions can be defined in different ways. The main moral theories connect the rightness of actions with the observance of virtues, the fulfillment of moral obligations, and the avoidance of harm. When it comes to *legal* thinking, most liberal societies hold that countering harm to others should be the primary, if not the only, justification for the use of coercion and constraint.

SHOULD PEOPLE KNOW ABOUT THEIR OWN GENETIC MAKEUP?

Genetic disorders range from the fatal to the trivial and from the blatantly obvious to the virtually unseen. People who have fair skin have a greater inherited tendency to develop skin cancer than people whose complexions are darker, but this condition is seldom seen as a threatening genetic disorder. The prudential case in favor of knowing about one's genes can be put in its strongest form by studying a genuinely dangerous and universally frightening, instead of an unrecognized, affliction.

Individuals, for instance, whose tumor suppressor gene *p53* has undergone a certain mutation carry a disorder known as the Li-Fraumeni syndrome, which predisposes them to a spectrum of cancers. The syndrome burdens the individuals with a 50% risk of developing an invasive form of cancer by age 30 and a 90% risk by age 70. Although some of these cancers are curable, the accumulation and repetition to which the mutation predisposes individuals in the end make it lethal.[3] The prudential question is: should people know about conditions like this for their own sakes? One answer is that the knowledge would be beneficial because it would enable them to draw up their life plans realistically. Another response, however, is that if the information does not help people to improve their present or future physical condition, it is not only unwise but also unkind to make them aware of their true condition. It seems that especially when the condition is incurable, people cannot have an automatic prudential obligation to acquire the information.

Let us suppose, however, that the disorder is potentially fatal but curable or preventable if diagnosed at an early

stage. Assuming that people want to live long and healthy lives, it seems prudential for them to know about such a dormant condition. But there are 2 kinds of cases here. If the disorder can be removed and the ensuing disease prevented by 1 simple operation that does not pose serious risks to the patient, then all right-minded people have firm prudential grounds for finding out about the condition of their genes. If, however, the treatment is ineffective, painful, or difficult to obtain, the grounds are less firm.

An additional aspect is that diseases are seldom the result of genetic disorders alone; environmental, psychological, and social factors can also contribute to the emergence of basically hereditary ailments. When the prevalence of the actual illness depends on these other factors, it can be argued that people should know about their genetic weakness because the knowledge enables them to adjust their lifestyles accordingly. It can also be argued that if there is little that people can do to alter their circumstances, the information would be needlessly distressing. And even if they could alter their lifestyles, it is not clear that the knowledge is a blessing because people may enjoy their lives as they are and resent the idea of changing their behavior.

The relevant moral considerations regarding the duty to know about our genetic makeup include people's virtues and duties and the possible harm inflicted on others by the lack of knowledge. From the viewpoint of virtue ethics, it can be argued that persons of integrity should not be involved in any kind of self-deception and that they should not deliberately overlook facts about their own health status. Those who emphasize people's duties, in their turn, can state that we all have an obligation to protect others, and those who confine their attention to the undesired consequences of people's choices can argue that they should not inflict harm on others either by acts or by omissions if this can be reasonably avoided. But whom and to what degree should people protect from unpleasantness and harm?

If people plan to have children, there are cases in which they have a clear moral duty to find out about the genetic disorders that they carry. Future children are entitled to be protected from a disease that causes suffering but that could easily have been cured or prevented before their birth or early in their infancy. The case of incurable conditions is more difficult to tackle. Some theorists think it would be wrong to bring into existence someone who suffers from a genetic ailment when the alternative would have been to give birth to another child who is healthy. Others argue that even a life that contains suffering is better than no life at all and that the potential individuals who are not given the chance to live are wronged by the decision not to bring them into existence.

Although all main branches of ethics seem to oblige us to know about our genetic makeup, at least in some cases, no legal duties can be derived from these obligations. People cannot really be forced into moral integrity, and the harm inflicted on future children by a lack of genetic knowledge cannot be regulated with any accuracy. Parents can conceivably be blamed and even punished for harming their unborn or newly born children by direct physical violence, but it would be too complicated to prove that a genetic disorder results from a malicious, negligent, and deliberate decision not to know about one's genes.

SHOULD REPRODUCTIVE PARTNERS OR BUSINESS ASSOCIATES KNOW?

The individuals with whom people intend to have children and business associates both have, in their parental or professional roles, good prudential grounds for finding out about people's genetic disorders. Reproductive partners can legitimately try to ensure that the offspring they produce are healthy and do not have to suffer unnecessarily from hereditary diseases. Business relations have a well-founded interest in knowing whether prospective associates are able to keep their promises and fulfill their obligations.

The moral case that reproductive partners have for acquiring information concerning their partners' genes is strengthened by the interests of prospective children to be healthy, but it is also weakened by the fact that individuals have no moral obligation to produce offspring with other specified individuals. Partners can have a moral obligation to avoid bringing into existence a child whose genetic disposition makes her or his life miserable, especially if the alternative is to have a healthy child. But this obligation can be discharged by choosing another partner because it is nobody's duty to have children with specific people. If harm might befall individuals should their genetic disorder

be revealed, their reproductive partners can have no overall moral, let alone legal, right to know about them.

Economic considerations can make it desirable for employers, employees, business associates, and insurance companies to find out what genetic disorders individuals carry. Because some hereditary weaknesses, such as the mutation of gene *p53,* are possible causes of disabling illness and premature death, contracts and agreements that are made between people without knowing about such conditions can be highly unprofitable. These reasons can be seen as prudential or moral, depending on who will be harmed by a person's inability to fulfill a contract. If only direct business associates are harmed, then the reason is prudential; if the harm is extended to shareholders, clients, and employees, then the grounds for disclosure are moral.

But the obligation to protect others against economic loss is not as strict as the duty not to inflict suffering on innocent persons. All economic decision making is based on risk assessment, and from the point of view of business associates, the composition of people's genes is only one unknown factor among others in the cost-benefit analysis. Many people would, of course, like to ascertain the state of others' genes, but if this interest is founded on a desire to maximize economic profits, then almost any reluctance that people may have about parting with the information provides, both morally and legally speaking, a sufficiently good reason not to satisfy their curiosity. Grounds for such reluctance can be found in the distress that the knowledge can cause and in the fear of discrimination that can accompany the disclosure of people's medical status to others.

The representatives of insurance companies can argue that if people do not report their genetic disorders when they apply for life or health policies, other policyholders will be unjustly burdened by the unforeseen cost of medical treatment and premature death. If this argument is presented in the framework of consequences and harm, then the economic loss possibly inflicted on others is outweighed in a level-headed comparison by the distress caused by the unwanted knowledge and fear of discrimination. It can also be argued that life and health policies should not be made more expensive for those who carry mutated genes because many other factors besides the biologic determine whether people actually get ill. Genetic disorders cannot always be seen as diseases in their early stages. An obvious injustice related to differential insurance practices is that they punish those who are already genetically worse off by denying them life and health policies or by enlarging the payments.[4]

The insurers' appeals to justice can also be founded on the reciprocity of duties and rights favored by many moral philosophers. It can be held that we should not do to others what we would not like them to do to us, and that when people profit at other people's expense by refusing to disclose genetic weaknesses, they are violating this principle. The problem with this argument is that it is not normally considered unjust to collect a compensation when the terms of the policy are met. Insurance companies define the payments of life and health policies on the basis of epidemiologic data, and the expenses caused by known genetic disorders should already have been accounted for, at a general level, in the fees.

The only way to benefit unfairly at the expense of others would be, within the duty-based approach, willfully to conceal one's genetic condition from the underwriter. This is wrong within ethical views that absolutely condemn lying. The model applies to situations where would-be policyholders are explicitly asked by the insurance company to reveal the genetic disorders they know they have. But this kind of thinking creates more problems than it solves. Because individuals cannot have a legal duty to know about the condition of their genes, the prohibition against active lying generates a duty to tell only for those who have voluntarily acquired the information and for those who have been informed against their will. As for the latter group, a special legal duty to be truthful would be grossly unfair because members of this group would already have been victimized once if they had been tested without consent.[5] For those who have voluntarily tested themselves, the legal obligation to tell the truth would be equally indecent. It is, after all, in the best interest of society that its members freely acquire information about their health status. The duty of honesty would make it more profitable for individuals to remain in ignorance.

SHOULD HEALTH CARE PROVIDERS KNOW?

Those who provide health care needs have at least 2 good reasons for wanting to know about the composition of their patients' genes. Physicians can monitor their patients' health-related needs more effectively and offer more reliable treatments if they are fully informed about all the relevant facts. In addition, public health authorities can collect knowledge regarding the genetic makeup of the population and develop health care services that are likely to meet the future needs of citizens.

The hippocratic tradition requires physicians to be beneficent—that is, to provide their patients with the best treatment available.[6] Physicians can refer to this tradition and argue that to fulfill their duties, they should be allowed to know about the genetic disorders of their patients. But the significance of beneficence has been undermined by the introduction of the principle of autonomy to health care ethics. The principle of autonomy states that medical professionals ought to respect the self-determined, self-regarding choices of their informed and competent patients even if the choices in question are potentially harmful.[6,7] According to this maxim, people are entitled to remain in ignorance concerning their genetic disorders,

which means that physicians cannot use paternalistic arguments to back their claims that they should be informed about their patients' condition.[7(pp154-155)]

The work of public health authorities is often based on epidemiologic data that are acquired by gathering information about the health and illness of citizens. If this work promotes human well-being and reduces human suffering, then we are, to some degree, morally obliged to reveal facts that can help the authorities. Furthermore, if we believe that other people should not hinder public health programs by withholding personal information, then we, too, have an initial duty not to withhold information concerning ourselves. When it comes to absolutely binding moral duties and legally enforced obligations, however, the situation is different. The harm inflicted on others by the nondisclosure of genetic data is indirect and uncertain, whereas the harm inflicted on individuals with genetic disorders in the form of distress and discrimination is direct and tangible. The argument from the reciprocity of obligations is no more convincing. In an ideal world, people would do their best to help the public authorities in their attempts to provide better health care services. But in an ideal world, they would not have to live in fear of discrimination should they reveal their genetic ailments to potential employers or insurance companies.

WHO SHOULD KNOW?

Who, then, should know about people's genetic makeup, and why? If the picture given here is not distorted, we all have both prudential and moral reasons for knowing about possible genetic disorders. Reproductive partners, business associates, and health care professionals have similar reasons for acquiring the information. But when it comes to duties and rights that could be enforced by law, these reasons are not firm enough to support them. As long as people whose genes deviate from those of the average individual are likely to face suspicion and discrimination, societies cannot legitimately force people to know about their hereditary composition.

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